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ABSTRACT

Written for parents, the paper describes experiences of 16 parents of handicapped children. Discussion includes excerpts of parents' initial feelings at their child's diagnosis, their reactions (largely negative) to medical and other professionals, their growing awareness that their own instincts were of most value in raising the child, difficulty in finding helpful counseling, and sources of support found in other parents of handicapped children. Also noted are changes in nuclear and extended families as a result of handicapped members, including effects on siblings and on the marriage. Parents speak about changes in their lives, especially in their ideas of what is important, and about coping suggestions for new parents of handicapped children. (CL)

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PARENT TO PARENT: INSIGHTS FROM FAMILIES WITH EXCEPTIONAL CHILDREN

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INTRODUCTION

A few years ago, Erma Bombeck, in a serious moment wrote: "Most women become mothers by accident, some by choice, a few by social pressures and a couple by habit. This year, nearly 100,000 women will become mothers of handicapped children."

This booklet is dedicated to those mothers - and fathers. It is written by parents of handicapped children for parents of handicapped children - to share our pain, joy, fears, and skills. We hope that the combined voices of other parents will bring a measure of hope, comfort, and pleasure to you, and that you will gain strength from those who have walked along the same path you are now starting.

Joan Skilling

Joanne Pheeny

The participants in this study are 16 parents of handicapped children - 14 mothers and 2 fathers. The children's disabilities include: mental retardation, cerebral palsy, emotional disturbance, visual handicap, hearing impairment, learning disabilities, spina bifida, and multiple handicaps.

ACKNOWLEDGEMENT

We wish to thank the 16 participants in this study for sharing their deepest emotions about their handicapped children, and for giving their insights into raising a "different" child. Their words were so eloquent that we did not attempt to paraphrase or rewrite. Each page carries the threads of their feelings and ideas; we have merely woven them together.

Together, out of the darkness of your saddest days, you have woven a tapestry which will bring light to others. Thank you.

OUR DREAMS/THE REALITY

Each of us remembers clearly the dreams and expectations we had for our unborn child. For those of us who parent a handicapped child, the reality has often proved far different from those dreams. We have had to grow and change; to cope with new emotions and unexpected tensions. We are still learning...

We expected, every one of us, no more nor less than all parents do - a healthy, normal child. We read the right books, ate the right foods, waited and dreamed. We looked back into our childhoods, and forward toward the coming child, and his/her future.

> "I had a wonderful childhood, and I wanted my children to have the same."..."I grew up in a home filled with serious problems, so I longed for a 'normal' home life."....

"I think we dreamed of the perfect child."....
"...a bright, creative, talented child" whom we would give "a wonderful childhood with lots of opportunities and loving care."

So we waited, and dreamed our dreams of the coming child, and the childhood we would fashion with loving care. And then our child was born.... For some of us, the realization that our child was somehow different dawned slowly; some of us were told almost at once; and some of us waited years for a formal acknowledgement of our fears and doubts. But there was a moment for all of us when the ground beneath our feet shifted - someone told us that our perfect child was handicapped.

At that moment, often without realizing it, we added to our previous identity, a new one: parent of a handicapped child. Now, in addition to Dr. Spock, our mothers, and neighbors, we had a new group of people giving us advice - the

professionals. The ways in which medical professionals communicated with us in the early days had a strong impact on our lives, and our adjustment.

Some reached out to us.

"The most positive action at the very beginning was having a nurse hug and kiss me before we left...She didn't say a thing, but communicated so much, and I've never forgotten it."

Some medical professionals were "always honest, even when it hurt." They showed respect for parents, took as much time as we needed to explain fully, and answered all our questions. Sometimes they referred us to appropriate community agencies, or helped us to liaise with other doctors.

Some reached out; many - the majority - did not. For many of us, a difficult time was made

even more difficult by these professionals. Many doctors did not give us the information we needed about our child's problems, saying later, "I didn't know how to tell you." Some ignored all symptoms of developmental problems, and judged the parents to be over-emotional or exaggerating.

> By the time .... was three, "the pediatrician had almost convinced me that I was crazy. He couldn't see the things I observed daily."

Often, there was an absence of any empathy for the families, and what they were experiencing.

> "No one ever asked how I was feeling, put an arm around me or showed concern for what we were going through. Those early days were like a nightmare; we kept expecting to wake up and find the pain gone."

As the years have passed, we have had many encounters with "professionals." Most of us have

found teachers and therapists, the "hands on" people who work most closely with our children, to be the most supportive. Many of them have been open and honest about our children's progress, willing to discuss our concerns, respectful and non-judgmental toward us as parents.

It is the school administrators and doctors who have most often been lacking in skills of communication with parents. Some have been ill-informed; others - "arrogant", "condescending", "inflexible", "dogmatic", and "patronizing." One guidance counselor told a parent who expressed concern over her son's learning problems, "Mother, you're just being a mother."

We have realized over the years that many professionals...

> "really can't understand the problem because they have never had to live every day with it."

"I don't think most professionals have a feel for the problems parents face daily." ..."Their insensitivity burdens an already over-wrought family."

The attitudes of professionals toward parents of handicapped children have begun to improve. However, most of us have learned that some are better than others, and that we cannot look toward professionals for all the answers. We have grown to realize our own instincts and insights offer our child as much or more than "generalizations" and textbook learning.

"I looked to professionals to tell me how I should raise this 'special" child. I thought they had all the answers. I have come to realize that the natural feelings in child raising are the most important."

SUPPORT

Some of us turned, or were directed, toward professional counseling to help us adjust to the problems and feelings of parenting a handicapped child. But most of us found that it was extremely difficult to find "good counselors." "Going shopping for the right or best counselor is expensive" and time-consuming. Many of the counselors we met "seemed uninformed - all book-learning, no real experience or understanding of everyday trauma."

Some counselors seemed "narrow-minded and opinionated," offering generalized advice which did not fit our needs. Getting counseling required time away from our families, time that some of us could ill-afford in an already overloaded schedule. Normal siblings sometimes resented yet another demand on our time and attention.

A few of us were lucky, and did obtain the help we needed.

> "The counselor helped me find myself again, and begin to look toward my own needs, and how to fulfill them."..."He helped me rebuild my self-confidence and problem-solving abilities."..."My husband got insight into himself, and also began to realize my needs."

Another avenue of support is community organizations for families with a handicapped individual. The appendix lists names and addresses of those organizations which our respondents found most helpful.

The addition of a handicapped child to the existing family structure was like the proverbial pebble dropping into the water. For good or ill, it caused ripples which extended into every aspect of family life. We often looked outside our nuclear family for support - from friends, extended family.

other parents of handicapped children, or God. Many of our friends rallied around us in the beginning during the initial crisis, but were unable to "go the distance" and offer continued support.

> "Most of our friends are interested mainly in success stories - triumph over adversity. They have no stomach for the reality of our lives. We never triumph; we only endure."

Those friends who were able to give continued support made an immeasurable difference in the quality of our lives, and in our ability to cope with day-to-day problems.

> "They acknowledge the difficulty of the situation," listen to us in a "non-judgmental way", offer "care, concern, and encouragement."

The strongest support by far came from people like ourselves - other parents of handicapped children. "They have know-how, experience, and

serve as role models." We look to them for knowledge of community resources, coping skills, and the understanding which seems to come only from "those who have been there."

OUR FAMILIES - NUCLEAR AND EXTENDED

The effects of our handicapped children were not felt by us alone; our extended families grieved also. Some have been able to "accept and love the handicapped child as he is" while others have been unable to bridge the gap between their dreams and the reality. Some of our relatives have been unprepared for the changes in us.

> "My dad keeps looking for his old daughter, the woman I used to be, brimming with self-confidence and enthusiasm, recounting amusing anecdotes about life. But that woman will never return; she is irrevocably changed."

Many of us looked toward our spouse to share our deepest feelings, and some of us found the bonds of marriage becoming stronger despite the difficulties. These parents share deep joy in their child's progress, or recovery from serious illness.

> "Some nights we just stand over his bed and watch him sleep. I guess we feel more blessed that he survived than cursed because he's handicapped."
>
> "The marriage is strengthened so long as both partners communicate their anxieties fully and honestly. With understanding of each other, the marriage grows and becomes stronger."

Many couples were unable to reach this ideal however, and found that the addition of a handicapped child to the family created fertile ground for conflict. Parents sometimes "turn undirected anger and frustration toward each other." There

is often "unspoken guilt and blame" over the reasons for the handicapping condition. The extraordinary problems of raising the different child cause "differences in philosophy" and disagreements over the handling of difficult situations. Often, the daily burden of caring for the child rests on the mother's shoulders, filling her life and thoughts. The mother can become resentful of her husband's "freedom and scope of opportunities." The family unit becomes weaker in situations where "someone always has to stay home with the handicapped child." A sound piece of advice mentioned repeatedly in this survey is "Get a sitter and get out."

Added to these stresses are problems with siblings. Many of them feel strong "resentment for the extra attention and time" required by the handicapped family member. They feel "left out" and "jealous." Sometimes the siblings

develop "false feelings of superiority" because of their obvious skills and achievements as compared to their sibling.

Although many siblings suffer embarrassment when they bring their friends home, many become the "protector when their sibling is threatened" in any way. Many siblings appear to realize and appreciate the ease and normality of their own lives.

Some siblings have developed a caring attitude and empathy toward their brother/sister which has been a model for people outside the family in their approach to the handicapped child. One parent sums up the reactions of her older children to their handicapped sibling:

> "Each of the four siblings has appeared to experience disappointment, sadness, fear and embarrassment; but I don't consider these necessarily negative. They have been

part of growing for all of us."

In that process of growing, many of us have found that our feelings fluctuate greatly.

> "At first, I found it difficult to be in the same room with him. It was a constant reminder of his loss."..."The whole experience of having a handicapped child is like being on an emotional roller coaster."

Parents speak poignantly about the low points on that roller coaster:

> "Our initial hope of progress turned to disillusion."..."There are more periods of anger and resentment, saying, 'Why me?'"..."I am envious of 'normal' parents whose lives seem so easy compared to ours."..."It is hard to watch a younger child who has accomplished so easily that task that B. has been struggling so hard to achieve."..."My negative feelings surface strongly when

dealing with bureauocratic agencies. There appears to be so much emphasis on forms and paperwork, while the child seems to get lost in the process."..."The daily, weekly yearly grind wears me down."

Yet, despite the pain, we have discovered compensations. Many of us have become "more accepting of handicapped children in general, and of "our own child's handicap."

"Initially, it seemed overwhelming as I tried to 'raise my child' in those first few weeks...Now K. is so much 'bigger' than any problem she could have."

"I take a measure of pride in all we have accomplished with our son."...I am finally beginning to "see the light at the end of the tunnel."

For all of us, the end of that tunnel also holds darkness - our fears for our child's future.

and our own. We have many. We fear that our child:'

> "will never be independent"..."will be mocked by peers"..."may get into trouble with the police"..."may hurt someone physically"... "will be lonely and unfulfilled"..."will not achieve his dreams"..."may need to be institutionalized."

For ourselves, we sometimes fear that our "feelings of hopelessness will grow;" that we will "grow more bitter and resentful over the years." We dread "the sadness and pain the future will bring." Some of us fear that we "will not live long enough to see our child grown up and successful," that "we will never have a future of our own," never be an "empty nester." Some of us feel compelled to "do all I can now, so I'll have no regrets later."

All of us seem to realize, with varying degrees of fear and pain, that all our lives we will bear

the responsibility for a child whose future is cloudy and uncertain. We wonder if the day will ever come when we can pursue our own dreams. Most of us have fears that extend even beyond the grave. "Who will look after our child after we are gone?"

Our many experiences, both positive and negative, in parenting a handicapped child have changed us, and altered our ideas about what is important in life. Parents speak eloquently of these changes:

> "I find myself much more tolerant of children's differences."..."...helped me to realize handicapped people can be real contributors in spite of their handicap."..."I am learning to look inward rather than judge the external appearances of both people and situations."

> "Priorities are radically changed. Tolerance of petty concerns is minimal. This is one positive side effect of having a handicapped

child. We work hard but we play hard too and become more aware of all that is good in life."..."Little things have become so much more important! Each little change has become a great milestone in our lives."

Sometimes these changes have put greater distance between us and our friends...

"Sit around a bridge table some night listening to the mothers of normal children. There is competition among them as to what reading group their child is in, and who hit the home run...They don't realize how lucky they are that their child <u>can</u> read and run, let alone run fast - and that these are not the important things in life. As the parent of a handicapped child...you don't take anything for granted...Love, family, good health are all you ask for and need."

COPING

As we change, we also grow. We grow in our abilities to cope with the intricacies of raising a different child. We develop inner resources which help us to integrate the handicapped child into the existing family structure. We "find ourselves" again, make plans and pursue interests of our own. We take many steps along the road to what the professional literature calls "acceptance," even as we realize that this acceptance can never be final. We have learned to accept the reality of our changed lives, but continue to mourn what we - and our children - have lost.

When asked what advice they would give to the new parents of a handicapped child, our respondents had many ideas. Certain themes appeared over and over again, and are marked with a * in the following list:

1. *Learning to accept and to cope is hard work. Take your time learning to adjust; don't be pushed.
2. *Meet and talk with other parents of handicapped children. Join parent support groups.
3. *Take one day at a time.
4. *"Learn as much as you can about the handicap. Don't count on anyone educating you about it."
5. *Find a good friend, someone you can talk to, cry with, lean on.
6. Get help right away if you need it; sometimes you can't "go it alone."
7. Love your child as a child. "So often the handicap overpowers the fact that the child is a child first."
8. "Get a good sitter and get out."
9. Talk to your spouse about your concerns.
10. "Learn to emphasize the child's strengths to him and yourself."
11. Don't be afraid to ask questions of professionals. Ask again if you don't understand the answers.

12. Look inside yourself for your strengths.
13. Don't be ashamed of your child.
14. Learn how to deal with people effectively, and how to fight for your child's rights when necessary.
15. "Cry with him and laugh with him."
16. Talk to siblings about their feelings; give them a chance to express negative feelings.
17. Accept your own negative feelings; don't feel guilty.
18. Give your child as normal an environment as possible.
19. Beware of over-protectiveness.
20. Rely on God, especially when you are the most down, to carry you through.
20. "No matter how bad it is, when you come out of the horror to the other side (acceptance), you will be a much stronger person."

AFTERWARD

As we read over these suggestions, and all that the parents have shared in this booklet, we remember the mother who said, "We never triumph; we only endure." We understand what she was feeling as she wrote that, but we believe she was wrong. She, and the other parents who contributed here, are learning, growing, changing and sharing. They have gone far beyond endurance; they have triumphed.

APPENDIX

Parent support groups and local, state or national organizations for handicapped individuals.

1. Parent Educational Advocacy Training Center
   228 S. Pitt Street
   Alexandria, VA. 836-2953

2. ACLD
   5225 Grace Street
   Pittsburgh, PA 15236

3. Child Development Center of Northern Virginia
   111 North Cherry Street
   Falls Church, VA 22046 534-5353

4. CEC
   1920 Association Drive
   Reston, VA 22091 620-3660

5. National Federation of the Blind of the District of Columbia
   3417 Seventh Street
   North Arlington, VA. 525-5082

6. Public School Special Education Parent Teacher Organizations (phone your child's school for future information)

7. HEAR NOVA
   4712 Randolph Court
   Annandale, VA 22003

8. Northern Virginia Association for Retarded Citizens
100 N. Washington Street
Falls Church, VA 532-3214

9. Spina Bifida Association of America
343 S. Dearborn Avenue
Suite 319
Chicago, IL 60604 (312)663-1562

10. National Association for the Visually Handicapped
305 E. 24th Street
New York, NY 10010 (212)889-3141

11. Mothers of Downs Syndrome Children
c/o Northern Virginia Association for Retarded Citizens
105 E. Annandale Street
Suite 203
Falls Church, VA 22046